

SECTION 8

**DISABILITY,
EQUALITY & HUMAN RIGHTS:**

**ACCESS TO HEALTH AND SOCIAL
SERVICES IN
NORTHERN IRELAND**

**Literature Review-
Equality & Human
Rights: Access to Health
and Social Services in
Northern Ireland**

Disability, Equality and Human Rights: Access to Health and Social Services in Northern Ireland

The Department of Health, Social Services and Public Safety (DHSSPS) and its associated bodies and agencies have a statutory duty, under Section 75 of the Northern Ireland Act 1998, to have due regard for the need to promote equality of opportunity between persons with a disability and persons without. In addition to this, there are further duties under the Disability Discrimination Act 1995 to ensure that people with disabilities are not discriminated against in access to goods, facilities and services⁷¹.

The Human Rights Act 1998⁷² further promotes the rights of both disabled and non-disabled people⁷³. It is envisaged that the Act will continue to have a significant impact upon health and social services in Northern Ireland as the DHSSPS and associated bodies are obligated to incorporate, promote and protect human rights throughout health, social care and public safety legislation, policy and practice.

The Disability Discrimination Act, the Human Rights Act and Section 75 of the Northern Ireland Act are important instruments for ensuring that people with disabilities receive respect, dignity and equal treatment, in accessing and using health and social services. However, as the literature reviewed in this section will demonstrate, although substantial progress has been made in facilitating equality of opportunity for people with disabilities in health and social care, significant equality and human rights issues continue to exist.

The purpose of this section is to draw attention to these issues and to identify recommendations for improving equity of access to health and social services for people with disabilities in Northern Ireland. A number of themes are explored including an examination of the definition and measurement of disability; an

⁷¹ The Disability Discrimination Act (DDA) 1995, which applies in both GB and Northern Ireland, aims to end discrimination and provides disabled people with rights in the areas of employment, access to goods, facilities and services and buying or renting land or property. The final stage of the goods and service provision of Part III of the DDA will come into effect in October 2004. It is envisaged that this may have considerable financial implications for health and social services as steps must be taken to adapt the physical features of premises in order facilitate greater access.

⁷² the Human Rights Act 1998 came into effect on 2 October 2000.

⁷³ by incorporating the rights and freedoms guaranteed under the European Convention on Human Rights (ECHR) into domestic law.

exploration of common access problems encountered by people with disabilities; and, an account of access barriers arising from different types of disability (learning disabilities, visual and hearing impairments, HIV and AIDs, and mental health are explored). Issues relating to disability and multiple identity, disability and access to health and social services information, and disability and human rights are also briefly considered.

Defining Disability and Recognising Diversity

Whilst a wide range of themes are explored throughout this section it must be recognised that it *does not* provide an exhaustive list of all human rights and equality issues relating to disability and access to health and social services. There are many different types of disability and different routes into disability⁷⁴ and these factors along with other variables (such as gender, age, ethnicity, geographic location, socio-economic status and so on) can often generate different barriers to service access. It is therefore not possible, given time and resource constraints, to provide a fully comprehensive account of all the relevant issues.

There is no one universally agreed definition of disability^{75 76} and despite common misconceptions, disabled people are by no means an homogenous group. The dominant image of disability tends to be that of physical disability, however, it is vital to recognise that a range of other disabilities exist (for example, sensory disabilities, learning disabilities and mental illness).

Each type of disability or impairment can impact differently upon the lives of each individual. In addition to this, factors such as multiple disability (that is, having more than one type of disability), the degree of severity of the disability⁷⁷ and the stage in which a person becomes disabled⁷⁸ can also influence how disabled people access public services (Spollen et al, 2004:13).

⁷⁴ Some people may be disabled from birth, whilst others may become disabled through, for example, an accident.

⁷⁵ The Disability Discrimination Act 1995 defines disability as, "A physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities." (Equality Commission, 2003:3)

⁷⁶ The purpose of this section is not to debate the definition of disability in any great detail, but rather to acknowledge that it is a complex concept in which there is much debate regarding eligibility criteria (that is, which individuals and conditions should be included within the definition and which should not). A confused definition of disability can in itself create barriers to accessing services.

⁷⁷ Disabilities can range from mild to severe.

⁷⁸ Disabilities, for example, can be present from birth, acquired through the developmental period or emerge as a result of the ageing process (Spollen et al, 2004:13).

Zappone (2003:2) further suggests that people with disabilities can have very diverse backgrounds and very different experiences resulting from the complex interaction between their disability and other characteristics such as gender, age, ethnic identity, sexual orientation, marital status and so on (this section will later explore the emerging literature in relating to disability and multiple identity).

The inability of some health and social care providers to recognise diversity can have a profound impact upon the capacity of disabled people to access health and social services. Both Northern Ireland and UK-based research continues to suggest that many health and social care staff can display a lack of understanding and respect for people with disabilities. A qualitative study commissioned by the Department of Works and Pensions, for example, reveals that people with disabilities often feel that medical professionals display negative attitudes towards their disabilities including stereotyping and uncaring and unnecessarily strict treatment (Molloy et al, 2003:118-119).

Similar issues have been raised by people with learning disabilities in a consultative exercise organised by LEAD-NI⁷⁹ on behalf of the DHSSPS. Whilst many of the participants had good experiences of GPs and hospital staff in general, there were a number of instances of poor communication between health and social care staff and service users (DHSSPS, 2002:30).

This is evident from a number of comments made by participants:

“Staff can be cheeky”

“Doctors sometimes talk to the support worker and not to the person”

“If doctors understood more about disability they would treat us with more understanding and respect”

(Comments made by participants in the LEAD-NI consultation)

The DHSSPS, HSS Boards and Trusts and other health and social services bodies and agencies have, through their Section 75 duties, undeniably made significant progress towards developing

⁷⁹ Northern Ireland Coalition on Learning Disability

equity in access to health and social services for people with disabilities. For example, through staff disability awareness training and by consultations with disability groups and organisations on a range of issues.

However, it is evident that statutory health and social services in Northern Ireland must continue to strive towards achieving a cultural shift within the HPSS in regards to the perception and treatment of people with disabilities. There must be a renewed drive towards educating staff of the diverse needs of people with disabilities particularly in terms of accessing and utilising health and social care. Mechanisms should be developed to greater facilitate the involvement of people with disabilities in service planning and decision-making. A number of recommendations in relation to these issues have been outlined below and overleaf for consideration.

Recommendations: Disability Awareness and Recognising Diversity

- **A renewed emphasis on providing disability awareness training for HPSS staff. Training should promote an understanding of the perspectives of people with different types of disability and “multiple identities” (Molloy et al, 2003:157). Disabled people themselves should be involved in the design and delivery of training for HPSS staff. Staff should be encouraged to gain experience of disability through visits to day centres, disability organisations and so on.**
- **Develop new and innovative ways to consult and listen to people with disabilities, people with disabilities are often frustrated that non-disabled people consistently make assumptions about the needs and capabilities of disabled people without consulting disabled people themselves (Molloy et al, 2003:157).**
- **Develop new and innovative ways to involve people with disabilities in service delivery, particularly in regards to designing and delivering services. This should be done through increased engagement with disabled groups and organisations with a focus on identifying models of good**

practice (Molloy et al, 2003:157).

- **DHSSPS should, in collaboration with other HPSS bodies and disability groups/organisations, encourage membership of self-advocacy groups amongst people with disabilities in order that they may develop the self-confidence and the skills required to talk and be listened to (LEAD-NI, 2002:27).**

Measuring the Extent of Disability in Northern Ireland

The lack of a clear and consistent information based on the prevalence and circumstances of disability in Northern Ireland can have a detrimental impact upon the planning, delivery and evaluation of services for people with disabilities (Monteith & Kelly, 2003:1). Monteith & Kelly (2003:1) maintain that the collation of detailed information on disability in Northern Ireland is crucial for identifying areas of inequality and need and for targeting services accordingly.

Spollen et al (2004) in a recent review commissioned by the Northern Ireland Statistics and Research Agency (NISRA), identify significant information gaps in relation to disability-related data in Northern Ireland. The review report makes a number of recommendations regarding the collation and reporting of the incidence of disability. It would be prudent for the DHSSPS and its associated bodies to take note of the recommendations of this report (some of which are outlined below). Improvements in the collation of statistics on disability may lead to a greater identification of areas of inequity in access and use of services.

Recommendations: Measuring the Extent of Disability in Northern Ireland (Spollen et al, 2004:64-68)

- **All Government Departments (including the DHSSPS) should be reminded when gathering information in relation to their Section 75 duties to gather information in regards to whether or not individuals have a disability.**

- To consider that people with disabilities have multiple identities and hence details should also be gathered as regards to disabled people's gender, age, marital status, ethnic and cultural background, sexual orientation where possible.
- Alternative means must be made available to obtain information from persons with a disability in addition to the written word (for example, through audio cassettes, sign language interpretation). Likewise the dissemination of information must be made available in different formats.
- Future information gathering should distinguish between persons who have acquired a disability through ageing or illness and those who have been disabled from birth or soon after as the needs of these two groups are likely to be quite distinct.
- More information is required about people in a caring role and their needs for services and support, this information should be gathered separately and not inferred from information about the person with the disability.
- NISRA should seek to convene an inter-departmental group to develop proposals for a disability specific survey in Northern Ireland to be conducted within the next two years.

Disability: Identifying Common Themes

Whilst people with disabilities have diverse identities it is evident that they do experience a number of *common* barriers to accessing health and social services. Molloy et al (2003) has identifies a number of these barriers including:

- **physical access difficulties** resulting from the architecture of facilities (for example, buildings with no wheelchair access);
- a lack of appropriate health and social care information in **accessible formats** (such as Braille, audio cassettes and

information specifically designed for people with learning disabilities);

- a lack of appropriate **adaptations and equipment** (primarily due to financial cost implications);
- inequities in access to services according to **geographical area** (with some people able to access help, support and equipment in some areas whilst access is restricted in others);
- inconsistencies in regards to the **level of support** for some disabilities but not others (for example, there is a perception that less support is available for people with mental health difficulties);
- **inadequate transport** to and from health and social care facilities; and,
- **a lack of consultation** in regards health and social care policy development and decision-making.

An additional persistent theme emerging from the literature review is the lack of information, advice and services for disabled people on sexual and reproductive health. Harley et al (2000) suggests that this is because society largely perceives disabled people to be asexual, childlike and innocent (cited in Brothers, 2003:52). Often health and social care providers assume that people with disabilities are not sexually active, thereby denying them access to appropriate sexual health and related services (for example, cervical screening, information on STIs, family planning services).

The DHSSPS Sexual Health Promotion Strategy and Action Plan consultation paper (2003), identifies a range of issues relating to disability and access to sexual and reproductive health services including:

- the lack of consistent **sex education** in day centres and special schools across Northern Ireland;
- inadequate access to sexual **health service facilities** including a lack of ramps and flat entrances to buildings, inaccessible

treatment rooms (including inaccessible treatment tables, equipment and toilets), and a lack of large print signs;

- a lack of access to sexual health **information and advice in appropriate formats** (such as Braille, audio cassette, information designed for people with learning disabilities);
- the potential for the **abuse of vulnerable adults, children and young people** due to their lack of access to information and knowledge on the issue; and,
- a **lack of information** for those who acquire a disability during their lifetime.

There is a significant dearth of information in relation to disability and sexual and reproductive health in Northern Ireland. This issue needs to be urgently addressed. It is recommended that the DHSSPS take a strategic approach to dealing with access barriers to key sexual and reproductive health services which should involve identifying areas of best practice⁸⁰. Further recommendations in regards this issue are outlined below for consideration.

Recommendations: Disability and Sexual Health

- **The DHSSPS in association with HSS Boards Trusts and disability groups/organisations should conduct a study and needs assessment of the sexual health, sex education and family planning needs of people with disabilities.**
- **Province-wide audience specific sex education and reproductive health programmes for people with disabilities should be designed and delivered in settings such as special schools, day centres, health centres etc.**
- **Design and promote a range of information and advice leaflets/videos on sexual health and disability. These should be produced in a wide range of formats (Braille, plain English, large print, audio cassette etc). Information**

⁸⁰ Some HSS Boards and Trusts have already developed initiatives and produced literature specially tailored for the needs of people with disabilities (for example, for people with learning disabilities).

on how and where to access appropriate services or further advice should also be included.

Access Issues by Type of Disability

People with disabilities can often experience different barriers to accessing health and social services dependent upon the nature and extent of their disability. Access barriers arising from four particular types of disability (learning disability, visual and hearing impairments, HIV and AIDS and mental health) are now briefly explored for illustrative purposes. However, it is crucial to bear in mind that this is by no means provides a comprehensive account of the many diverse types of disability and barriers to service accessibility.

Learning Disability

Mencap (2004:2) maintain that very little guidance exists to date, as to how health and social services should meet the needs of people with learning disabilities and their families in Northern Ireland⁸¹. Additionally, a report by LEAD-NI further indicates that people with learning disabilities have had limited opportunities to contribute to HPSS policy formation and decision-making (2002:6).

The LEAD-NI (2002:6) report identifies a number of factors which can be attributed to this exclusion including:

- the attitudes of others regarding the ability of people with learning disabilities to participate and make a valuable contribution;
- the absence of information in accessible formats; and,
- the availability of appropriate transport (which prevents participation).

In terms of actually accessing and using health and social services, the LEAD (NI) report identifies a wide range of problems

⁸¹ The report does, however, acknowledge that the current *Mental Health and Learning Disabilities Review* includes the physical health of people with learning disabilities within its programme of work.

experienced by people with learning disabilities. These difficulties (which are explored briefly below and overleaf) relate the range of activities available in day centres; interaction with health and social care staff; attitudes towards special hospitals; the inaccessibility of A&E services; and, the need for improvements in advocacy and support.

Difficulties in Accessing and Using Services Experienced by People with Learning Disabilities (LEAD-NI, 2002):

Day Centres – participants reported that there are often only a limited range of activities available at day centres. Many stated that they would like day centres to be more active in providing a stepping stone to inclusion in the community which involved mixing with other disabled and non-disabled people. Other issues highlighted included the embarrassment of marked transport taking people to and from the centres, problems getting to and from day centres particularly for people in rural areas, and the reduction in the number of places in day centres.

Interaction with HPSS staff – whilst many respondents expressed satisfaction with HPSS staff, others mentioned difficulties with staff, particularly doctors, who did not listen to their wishes. A lack of information to make informed choices was identified as an additional problem.

Special Hospitals – there was a widely held view amongst participants that special hospitals were unnecessary, the mere mention of them tended to evoke strong emotions of anger and fear in some people.

Accident & Emergency Services – the inaccessibility of Accident and Emergency Departments and the long waiting hours was believed to be particularly problematic for people with learning disabilities.

Advocacy and Support – there was an identified need to instil more self-confidence and skills in people with learning disabilities in order to encourage them to talk and be listened to.

Mencap in their reports *“Equal Lives” (2003)* and *“Treat Me Right!” (2004)* stress that people with learning disabilities tend to have poorer health than the general population. They are, for example,

more likely to experience weight problems (both obesity and low weight) and be prone to certain medical conditions (such as coronary heart disease, epilepsy, hypertension, skin disorders, dental problems, visual and hearing impairments, mental health problems).

The *“Treat Me Right!” (2004)* report maintains that health care staff are often inadequately trained to deal with people with learning disabilities. A survey conducted by Mencap involving 215 GPs, for example, found that 75% had received no training to help them treat people with a learning disability (Mencap,2004:16). The report highlights that the lack of training can lead to misdiagnosis, undiagnosis, inappropriate treatment or even no treatment at all.

The report further provides evidence of poor quality treatment in hospital care, particularly, a lack of help with eating and drinking, a lack of attention to administering medication and, expectations that the person’s family or care workers will continue to provide them with even the most basic care whilst in hospital. The report also identifies evidence of direct discrimination towards people with learning disabilities in hospital settings including “do not resuscitate” orders on medical records and refusals for life saving interventions such as heart surgery (Mencap, 2004:20).

The Mencap report *“Equal Lives” (2003)* identifies gaps in the provision of appropriate information on health issues for people with learning disabilities. The report also argues that the levels of funding and staffing of crucial therapy services for people with learning disabilities (for example, speech and language therapy, physiotherapy, occupational therapy) is inadequate (Mencap, 2003:9).

Both LEAD-NI and Mencap have made several recommendations aimed at facilitating more equal access to health and social services for people with learning disabilities. It is important that these recommendations are taken into consideration and urgent action taken to address the needs and service access barriers experienced by people with learning disabilities.

Recommendations: Learning Disability

Points highlighted by LEAD (NI):

Interaction with Staff

- **DHSSPS, HSS Boards and Trusts, must promote a change of culture amongst HPSS staff in order to tackle the preconceived notions of learning disabilities. Staff must provide, where possible, explanations regarding diagnosis and treatment to people with learning disabilities in an appropriate format.**

Day Centres

- **There should be an assessment of day centre activities with steps taken to introduce variety in the activities offered. There should be a drive towards more community based activities, more places at day centres, more staff members, unmarked transport to and from centres, and the provision of adequate money for attendance.**

A&E

- **There should be a review of the accessibility of A&E services for people with disabilities in terms of physical access. DHSSPS should provide information and advice on using A&E services and this should be accessible in a range of different formats (Braille, large print, audio cassette, plain English etc).**

Advocacy and Social Support

- **DHSSPS, HSS Boards and Trusts in co-operation with disability groups/organisations, should encourage and facilitate membership of self-advocacy groups in order that people with learning difficulties may have their voices heard on matters relating to health and social care.**
- **DHSSPS, HSS Boards and Trusts should encourage and facilitate a culture of volunteering in order to support the inclusion of people with learning disabilities and other people with disabilities into the community.**

Recommendations: Learning Disability

Based on recommendations from the “Equal Lives” Report (Mencap, 2003)

Health Checks

- **Development of adequately funded Northern Ireland wide three year trial “Individual Health Check Programme” for people with learning difficulties given that people with learning difficulties are prone to weight problems and certain other medical conditions (such as hypertension, dental problems, skin disorders).**
- **Health and social care providers should fund and implement a series of “Healthy Living Packs” in accessible formats individually tailored to meet the needs of both children and adults with learning disabilities.**

Therapy Services

- **A commitment to provide resources for specialist healthcare and therapy services for children and adults with learning disabilities. A commitment to identifying and recording unmet need, compiling and monitoring waiting lists of children and adults with learning disabilities.**

Long Stay Hospitals

- **A recommitment to resettlement from hospital accommodation on a timetabled programme, with the ultimate goal of closing long stay hospitals. This should involve committing to a partnership with people with learning disabilities, their families and carers in the planning and implementation of the resettlement programme. Provision of specialist support to family and carers in regards to the care of individuals resettled from hospital.**

Partnership

- **DHSSPS, HSS Boards and Trusts to work in partnership with people with learning disabilities and their families in order to, develop a range of day time and leisure activities.**

Recommendations: Learning Disability (Mencap,2004: “Treat Me Right!” Report)

Staff Training

- **Improved training in learning disabilities for all health and social care staff. This should involve practical training involving people with learning disabilities. Health and social care staff should also be aware of the types of conditions people with learning disabilities are susceptible to and must be able to recognise these conditions.**

Longer and Flexible Appointments

- **Many people with learning disabilities have difficulty articulating their symptoms, people with severe and profound learning disabilities find long delays in waiting for appointments particularly stressful. Allowing additional time in appointments or organising appointments at the beginning or end of the appointments schedule may improve the experience of people with learning disabilities.**

Accessible Information

- **Service user information should be provided in accessible, easy-to-read formats, this should include providing more accessible information on medications.**

Screening Programmes

- **All screening programmes must ensure that people with learning disabilities have the same access rate as others (for example, in relation to cervical and breast screening programmes).**

Visual and Hearing Impairments

People with visual and hearing impairments experience a range of problems in accessing health and social services. A study published by the University of Manchester National Primary Care Research Centre and the Central Manchester NHS Primary Care Trust (2003)⁸², for example, identifies a number of difficulties

⁸² random sample of 98 profoundly deaf people living in North West England

encountered by deaf people in accessing primary care and Accident and Emergency Services including:

- a lack of access to professional interpreters, with many people tending to rely on relatives and friends for their interpretation needs;
- a lack of visual patient call systems in waiting areas (service users often have problems knowing when it is their turn to be seen as staff either call out their name or announce it over a speaker system); and,
- difficulties obtaining information and in communicating with staff in regards to treatment and medication (a particularly acute problem for people with hearing impairments attending services on their own).

The report makes a number of recommendations for improvements in services for people with hearing impairments. However, it must be noted that many primary care and Accident and Emergency facilities in Northern Ireland already have adequate guidelines and arrangements for people with hearing impairments.

**Recommendations: Access to Health and Social Services
(National Primary Care Research and Development Centre,
University of Manchester & Central Manchester NHS Primary
Care Trust, 2003)**

- **Sign interpreters should be offered for any patient who needs one.**
- **All staff who work directly with patients should receive deaf awareness training (particularly medical staff).**
- **All Accident and Emergency Departments and GP surgeries should possess a textphone which should be made available to patients who wish to ring out, as well as those ringing in.**
- **All Accident and Emergency Departments and GP surgeries should consider installing a visual patient call**

system.

- **All deaf people should be given information about after care and the use of medication in writing before they leave the premises. This information should be in plain English.**
- **All Accident and Emergency Departments should have a policy on access to deaf people and should include guidelines for staff.**
- **The views of deaf patients should be sought in order to identify ways in which services can be improved.**

A report published by The Guide Dogs for the Blind Association reveals that more than a third of people with visual impairments felt that their GP were not fully aware of their needs (Nzegwu, 2004)⁸³. The study also found that whilst most blind and partially sighted people were satisfied with services from the GPs, many identified number of areas in which services could be improved.

Specific problems identified in the report included:

- limited physical assistance offered by staff (for example, assisting people with visual impairments from the seating area to the consultation room);
- limited staff awareness of the needs of people with visual impairments; and,
- a lack of information in preferred format (for example, the availability of prescriptions and registration forms in Braille or large print).

In terms of hospital services, the report highlights that the vast majority of service users did not receive letters of admission or other appointment letters in their preferred format (such as Braille or large print) and that signage in hospitals was often unhelpful (difficulties locating reception desks and moving about the hospital were reported).

⁸³ The survey was administered as a 20-minute telephone interview to a total of 832 blind and partially sighted people on lists of voluntary local associations of blind and partially sighted people around the UK.

The report further maintains that there is inequity in service provision *between* people with visual impairments. The report suggests, for example, that there is a tendency amongst public service providers to render assistance more readily to guide dog owners than visually impaired non-owners (Nzegwu, 2004:5).

Several recommendations to improve access for people with visual impairments are made in the report. A number of these recommendations are outlined below for consideration. Again, however, it should be noted that many statutory health and social service facilities do have policies aimed at improving access to services for people with visual impairments.

**Recommendations: Visual Impairments and Access to Health and Social Services
(Nzegwu, 2004)**

- **Need to plan and deliver a campaign aimed at generating greater awareness of issues relating to visual impairment within health and social services. This should incorporate visual impairment training for frontline staff.**
- **The development of detailed access guidelines for GP surgeries and other provider settings is needed.**
- **There is a need to raise awareness of the issues confronted by, and the specific needs of, blind and partially sighted people who are *not* guide dog owners.**
- **The inclusion of questions relating to visual impairment must be included in patient satisfaction surveys.**
- **An effective and responsive complaints system should be accessible to blind and partially sighted people.**
- **More in-depth research is needed to explore specific features of care provision.**

HIV & AIDS

A guide by the National Aids Trust (NAT) highlights that living with HIV can be extremely difficult for individuals and their families and that people diagnosed with HIV face a range of social, clinical and economic challenges (Anderson, 2004:5). It is evident from the guide that access to a range of support services is essential in order to improve the lives of individuals with HIV and their families.

Such services include:

- **psychological and emotional support;**
- decent and appropriate **housing;**
- help with **personal care** and day-to-day activities (such as cooking, childcare);
- **financial security** and independence (for example, flexible benefits system as poverty is a common problem for people with HIV); and,
- **family support services** (given that many women who are HIV positive may wish to start families).

However, the guide reveals that many people with HIV often do not know how to access services or do not know what services they are entitled to. Furthermore, many people do not have the confidence or skills (including language skills) to access services or may not have the resources to get to services (for example, a lack of transport).

The inflexibility of some services can be additionally problematic for those with children or those in employment and interactions with service professionals can be strenuous if staff are dismissive, insensitive or discriminatory (Anderson, 2004:18).

A recent report by the Health Protection Agency reveals a continued rise in new diagnosis of HIV in Northern Ireland⁸⁴ (DHSSPS Press Release, November 2004). The issues

⁸⁴ there have also been similar increases in the rest of the UK. The cumulative total of HIV infected individuals, whose first UK diagnosis has been made in Northern Ireland, reached 322 cases by 30 September 2004.

highlighted by the National Aids Trust (NAT) guide are therefore likely to become increasingly significant as the number of people with HIV in Northern Ireland increases. The DHSSPS and associated bodies must continue to ensure equity of access for people with HIV and AIDS and their families and must plan for future service needs.

Mental Health

A report by the Northern Ireland Association for Mental Health (NIAMH), entitled *Time for Change*, highlights that there is a common perception that mental health services are not designed around the needs of the service user. Additionally, the report suggests that there is a further perception that psychiatric hospitals, in particular, may not necessarily be therapeutic environments (NIAMH, 2003:14)⁸⁵.

In terms of access to mental health services, *Time for Change* suggests that there is:

- a lack of access to **crisis intervention** services and multi-disciplinary **community based support**;
- a lack of access to **relevant information** (including information on diagnosis, medication, treatment options, access to services, admissions/discharge, accommodation, benefits);
- inadequate access to **24/7 services**;
- inadequate access to **advocacy services**;
- a chronic lack of access to mental health services for **children and adolescents**;
- a lack of **community based** mental health facilitates; and,
- a lack of access to appropriate support for **victims of violence**.

NIAMH (2003) have made a number of recommendations improving access and facilitating equity to services for people with

⁸⁵ with patients expressing concerns over negative ward environments, boredom, views not being considered in treatment programmes, lack of one-to-one interaction with staff, and a lack of clarity regarding admissions and discharge.

mental health needs in Northern Ireland. A number of these recommendations are outlined below for consideration.

**Recommendations: Mental Health
(NIAMH, 2003:6-8)**

- **Services users must be properly recognised as experts of their situation in their own right. They should be provided with a real input into the design and delivery of mental health services.**
- **There is a need for a radical review of current hospital provision with a need to address the shortage of community-based facilities in Northern Ireland. Finding alternatives to hospital care is a key priority and key lessons should be drawn from examples of best practice elsewhere.**
- **There is a real need to provide crisis intervention services in Northern Ireland with an aim to support individuals in their own homes.**
- **The rights of users to access information is a priority. Clear and accountable systems of communication must be developed.**
- **A range of out of hours services should be developed for people with mental health needs.**
- **Every service user should have access to an independent advocate. There is a need for more advocacy services, these should be publicly monitored and evaluated to ensure a quality service.**
- **All mental health services in Northern Ireland should be co-ordinated, coherent and accountable. Accountable systems of care should be provided in Northern Ireland incorporating the best elements of clinical governance in other parts of the UK.**
- **Mental health promotion and prevention initiatives must be better co-ordinated.**

- **There is a significant gap in mental health services for children and young people. Specialist services must be developed in this area.**
- **Any future mental health services development should consider and recognise the complex and challenging needs of those affected by the “troubles”.**

For a number of groups, access to mental health services can be particularly restricted and, in some cases, culturally inappropriate. Black and minority ethnic people with mental health needs, for example, experience a number of pre-admission and after care factors which can affect both access to, and quality of, mental health care.

Such issues include, the stigma in some black and minority ethnic communities associated with mental health; language difficulties in communicating with health and social care staff; unfamiliarity with the mental health system and services; diversity in concepts of mental health; and, concerns regarding the ability of services to meet expectations of privacy and dignity (Centre for Ethnicity and Health & University of Central Lancashire/Mental Health Act Commission/National Institute for Mental Health in England, 2003:2).

Due to time constraints it is not possible to examine all the relevant issues relating to black and ethnic minority people and access to mental health services in detail. It is recommended that the DHSSPS and associated bodies take cognisance of the wealth of research, strategies and action plans emerging from the NHS in England, Scotland and Wales in regards to black and minority ethnic mental health⁸⁶.

Research into inequities and barriers to mental health services for other groups, for example, people in rural areas, children and young people, people in lower socio-economic groups should be commissioned.

⁸⁶ For example, see the National Institute for Mental Health in England Black and Minority Ethnic mental health web pages - www.nimhe.org.uk/priorities/black.asp

Recommendations: Mental Health

- **DHSSPS and associated bodies take cognisance of the wealth of research, strategies and action plans emerging from the NHS in England, Scotland and Wales in regards to black and minority ethnic mental health. Evidence of best practice should be identified and ways of engaging with the black and minority ethnic communities should be sought in developing services.**
- **Research should be commissioned to identify barriers to mental health service access for other groups such as, those in rural areas, children and young people, older people, LGBT people, people with multiple disabilities, people who are homeless, those in lower socio-economic groups and carers.**

Disability and Multiple Identity

It is important to recognise that there is often a complex overlap between disability and other variables such as gender, age, ethnicity, sexual orientation and so on. The interaction of these many facets of identity can often result in quite distinctive barriers to health and social services. The following section provides a brief review of existing literature relating to multiple identify and access to health and social care.

Disability & Gender

There is a significant lack of research and literature on the experiences of disabled women in Northern Ireland, particularly in regards to barriers which prevent access to health and social services.

Much of the available research and literature on women with disabilities tends to be derived from national and international sources. The US Center for Research on Women with Disabilities (CROWD) website, for example, identifies a comprehensive range of issues impacting upon the lives of women with disabilities.

CROWD, for example, highlight that:

- disabled women are more likely to have low levels of **physical activity** than non-disabled women;
- obesity continues to be a significant problem for women with disabilities who face significant barriers in **weight management**;
- women with physical disabilities have higher rates of **depression** than non-disabled women;
- little is known about the effects of the **menopause** or the treatment of its symptoms on disabling chronic conditions; and,
- disabled women, like non-disabled women, are likely to experience **emotional, physical and sexual abuse**.

In terms of sexual and reproductive health, CROWD, also reveal that there is a lack of information and research on **safe and effective contraceptives** for disabled women and a lack of information and research on the **fertility problems** experienced by disabled women.

CROWD further suggest that:

- disabled women are more likely to be forced or pressured into **unnecessary abortions, sterilisation and hysterectomies**;
- disabled women are less likely to receive **information on sexual and reproductive health** (health care providers often assume that women with disabilities are not sexually active, therefore they are less likely to offer those women information on birth control, safe sex practices and sexually transmitted infections);
- disabled women experience barriers to **obstetrical and gynaecological services**. Women (especially those with mobility impairments) are less likely to receive breast or cervical cancer screening (primarily due to inaccessible examination tables and equipment); and that,

- disabled women tend to have **negative experiences in pregnancy and childbirth** due to difficulties in finding health care providers and hospitals with the knowledge and equipment to manage pregnancy and childbirth in women with disabilities.

A recent report by the Equality Commission for Northern Ireland (2003) confirms that many of these difficulties are experienced by disabled women in Northern Ireland. The negative attitudes of health and social care providers was a common theme identified by the participants in the Equality Commission's focus groups (Equality Commission, 2003:19). The report also confirms the difficulties experienced by disabled women in accessing appropriate sexual and reproductive health care due to physical barriers such as inaccessible examination tables and equipment (Equality Commission, 2003:20).

The Equality Commission report further highlights the difficulties experienced by many disabled women in terms of accessing appropriate pre- and post-natal care. Many of the participants felt that wider society tended to them for their desire to become mothers. As one participant noted,

“Disabled women are thought of as needing care and are not envisaged to have children or a relationship”.

The issues highlighted by both CROWD and the Equality Commission have important human rights implications. The encouragement of unnecessary sterilisations and hysterectomies, for example, could contravene Article 12 of the European Convention on Human Rights (that is, the right to found a family) and Article 8 (the right to respect for private and family life). Inaccessible screening facilities and equipment or negative attitudes of staff towards disabled women's access to sexual or reproductive health services could have implications in regards to Article 3 (protection from inhumane or degrading treatment).

These are important issues for health and social care providers to consider if they wish to avoid potential costly legal action for human rights violations.

It is clear from the evidence presented that the DHSSPS and its associated bodies must take steps to address the inequities in

access to sexual and reproductive information and services experienced by women with disabilities in Northern Ireland. A range of recommendations for improving access are outlined below for consideration.

Recommendations: Gender and Disability

- **DHSSPS, HSS Boards and Trusts in association with Health Promotion Agency for Northern Ireland and relevant disability bodies and groups should develop a health promotion campaign specifically targeted at disabled men and women.**
- **DHSSPS, HSS Boards and Trusts should develop information packs/leaflets/web pages providing information on disability and the menopause. The information provided should be designed in appropriate formats (for example, audio cassette, Braille) and for a range of disabilities.**
- **DHSSPS, Boards and Trusts should provide information (for example, information packs/leaflets/web pages) on disability and sexual health. This should include information on contraception and other issues such as sexually transmitted infections (STIs). Information should be designed in appropriate formats and for a range of disabilities.**
- **The possibility of providing workshops for people with disabilities on sexual and reproductive health in different settings (day centres, health centres etc) should be explored. People with disabilities must be involved in both the design and delivery of such services.**
- **DHSSPS should conduct a review and needs assessment of disabled women in relation to gynaecological and obstetric care. This must include a review of medical equipment (such as examination tables, mammography equipment) used in screening procedures, as evidence suggests that disabled women frequently find such equipment inaccessible. It must also review the experience of disabled women in relation to pre- and post-natal care**

and identify areas for improvement.

- **DHSSPS, HSS Boards and Trusts in co-operation with other Departments and the voluntary and community sector must explore ways of addressing the needs of disabled women in relation to domestic abuse, including making available information and counselling services specifically designed and targeted at women with a range of disabilities.**

Men with disabilities, like women with disabilities, are a diverse group. Some disabled men, for example, have been disabled from birth whilst others have become disabled through accidents or work related illnesses (White, 2001:20). The type of, and route to disability, along with other factors such as age, ethnicity, or economic status, can impact upon how disabled men access health and social services.

However, there is considerably less information in relation to the disabled and their experiences of accessing health and social care compared to that of disabled women. This is clearly an area which requires a greater research focus.

Recommendations: Men and Disability

- **Research should be commissioned which explores the barriers experienced by men with disabilities in accessing health and social services in Northern Ireland. The research should focus on different types and routes to disability and how this impacts upon services accessibility. The experiences of older and young disabled men, gay and bisexual men, black and minority ethnic men, economically disadvantaged men and men in rural areas should be explored.**

Children, Young People and Disability

A 2002 report funded and supported by Barnardo's (NI), entitled "Is anyone listening?", explores the experiences of disabled children and young people and their access to public services (Monteith et al, 2002). The study reveals that disabled children and young people in Northern Ireland tend to feel "socially isolated and politically irrelevant". The study further highlights that public and professional understanding of the experiences of disabled children and young people, and their knowledge of the personal, social and economic impacts of disability remains limited (Monteith et al, 2002:7).

Monteith et al (2002:8) maintain that the experiences of children and young people with disabilities are very different and are determined, for example, by the type and extent of disability and the age of the child or young person. However, despite the diversity amongst disabled children and young people, a number of consistent difficulties experienced by both young people and their families have been identified by Monteith et al (2002:8) including:

- both parents and professionals **lack of knowledge** regarding their child's disability or condition;
- **social ignorance** and **prejudice** about disability in general;
- **parental relationship strain** and **family breakdown**;
- parents and young people's uncertainty about dealing with aspects of **growing up** (for example, dealing with sexuality);
- **social isolation** for both children, young people and their parents;
- **additional expenses** resulting from special diets, clothing, equipment (equipment and adaptations were found by the children and young people to be "boring" and "old-fashioned" with more modern alternatives requested);
- the **undue effort** involved in obtaining appropriate public services (including health and social services); and,

- access to health and social care particularly complicated as services are often provided across a number of different **programmes of care** (2002:65).

Kelly & Monteith (2003:1) in *“Supporting Disabled Children and their Families in Northern Ireland”*, further highlight that parents of disabled children and young people tend to experience poorly co-ordinated systems and inadequate services and that these problems are particularly acute during certain stages (for example, during initial diagnosis or during post school transitions).

Kelly & Monteith (2003) emphasise the importance of developing flexible, comprehensive, and family-based respite services which focus upon the needs and wishes of disabled children and young people. They further stress need for more information and assistance for parents of disabled children in applying for benefits, equipment and home adaptations.

The DHSSPS, HSS Boards and Trusts are currently addressing many of the needs of, and access barriers experienced by, children and young people with disabilities. The dependence to independence agenda, initiatives by HSS Boards to create registers of disabled people, the audit of equipment and adaptations, and the DHSSPS strategy for Children in Need are just a few examples of progress in this area.

However, unarguably there are many areas still needing to be addressed. Monteith et al (2003) make a number of recommendations for improving service access for children and young people with disabilities and their families. It is suggested that the DHSSPS and associated bodies take these recommendations into consideration in the design and delivery of services.

Recommendations: Children, Young People and Disability (Monteith et al, 2002)

- **Reduction in the high proportion of severely disabled young adults living in communal establishments must be hastened. This has been a long standing policy goal in the HPSS but progress is moving too slowly. The DHSSPS must look at ways of making significant additional**

investments to Boards and Trusts to promote independent living.

- **DHSSPS, HSS Boards and Trusts should conduct a needs assessment in regards to the domestic assistance required by parents and carers of children and young people with disabilities. However, consultation with the children and young people themselves must take place to ensure that such services are also acceptable to them.**
- **Development of a robust information system and the development of registers as a priority for HSS Boards and Trusts to facilitate adequate assessments of needs and planning of services for children and young people with disabilities.**

Other recommendations:

- **Development of an information base for parents and carers of disabled children and adults (websites, information packs) on a wide range of disabilities and impairments. An assessment of needs and support required by parents in cases where the child or young person has been newly diagnosed with a disability/impairment.**

A recent study commissioned by the Child Brain Injury Trust (CBIT) examines how children with an acquired brain injury (ABI) and their families in Northern Ireland perceive the standard of care they receive from health and social services (Anderson, 2003).

The study reveals that parents of children with acquired brain injury often experience feelings of being left “high and dry” (that is, abandoned and isolated) by health and social services particularly when their child is first discharged from hospital. This is primarily felt to be attributed to the lack of follow-up arrangements (Anderson, 2003:iv).

The study also highlights that parents are anxious about the lack of respite care and psychological support and have concerns regarding the lack of specialist support services within community rehabilitation services (Anderson, 2003:iv). Professionals

participating in the study identify the need for a dedicated Rehabilitation Centre for acutely injured children. (Anderson, 2003:iv).

Anderson (2003) makes a number of recommendations for improvements in access to services for children with ABI including, the need for increased resources; the need for interdisciplinary, integrated and comprehensive services; and, the need for awareness training for staff, including health and social care staff, in order to create a better understanding of the impact of brain injury. It is strongly recommended that the DHSSPS and relevant bodies take note of this report and its recommendations.

The Acquired Brain Injury study provides evidence of access barriers experienced by children and young people with one particular type of disability. It is acknowledged, however, that children with other forms of disability and impairments (for example, physical disability, learning disability, visual and hearing impairments) and indeed those with multiple disabilities, can experience quite distinctive service barriers depending upon the nature of their disability or impairment. However, due to time and resource constraints it is not possible to examine all these experiences within the context of this particular literature review.

Disability and Ethnicity

Until recently, very little research existed on the needs and experiences of black and minority ethnic people with disabilities. However, a number of studies have now emerged which provide a valuable insight into the complex interaction between disability and ethnicity (for example, Molloy et al, 2003; Pierce, 2003a, 2003b) in an Irish context.

Minority ethnic people and people with disabilities are often seen as two distinct and separate groups (Pierce, 2003:4). However, despite common misconceptions, Pierce (2003:4) maintains that minority ethnic people with disabilities are, "...a group with their own distinct identity, experiences and situation, a group exposed to multiple discriminations based on racism and disablism, and a group which poses very particular challenges to the design and implementation of equality strategies by employers and service providers."

A range of distinct difficulties experienced by black and minority ethnic people with disabilities have been identified (Pierce, 2003b:13) including:

- the **stigma attached** to disability and impairment within some minority ethnic groups;
- **social isolation** and the limited opportunities to meet or interact with other black and minority people with disabilities in similar situations; and,
- the reluctance of some minority ethnic families to **access services**.

In regards to the reluctance to access services, Molloy et al (2003:127) suggests that families of Pakistani and Indian origin are most reluctant to access and use public services believing that the care of the disabled person is primarily a family responsibility. Further, Pierce (2003b:19) highlights that the hesitancy of some black and minority ethnic people with disabilities to access services may be due to fear, suspicion or distrust of such services because of negative past experiences in other countries (for example, the experiences of refugees and asylum seekers).

Evidence suggests that some black and minority ethnic groups may be more reluctant to access services for people with disabilities than others. A study by Molloy et al (2003:127), for example, highlights that Asian people in particular believe that their community is:

- less **assertive** in accessing services;
- less **aggressive** when interacting with service providers;
- less likely to **complain** when there are delays in services; and,
- are less likely to **reapply** if services are initially denied.

The evidence presented by Pierce (2003a, 2003b) and Molloy et al (2003) demonstrates that, in terms of access to health and social services, there is clearly a need to identify and address both

the equality and human rights issues relevant to black and minority ethnic people with disabilities.

The DHSSPS, HSS Boards and Trusts have already taken a number of positive steps towards addressing the needs of minority ethnic people in Northern Ireland (for example, through the publication of policy guidance in accessing health and social services for asylum seekers and refugees, the publication of racial equality guidelines for racial groups, the development of regional interpreting services). However, there appears to be very little in terms of policy or service development specifically targeted at black and minority ethnic people with disabilities in Northern Ireland. It is, therefore, likely that significant gaps in service provision continue to exist for this group.

Pierce et al (2003b) has made a number of recommendations for improvements in health and social services for black and minority ethnic people with disabilities. These recommendations have been adapted to apply to services in Northern Ireland and are outlined below for consideration.

**Recommendations: Disability and Ethnicity
(based upon recommendations and suggestions made by
Pierce, 2003b)**

- **DHSSPS, HSS Boards and Trusts should work closely with disability groups/organisations and black and minority ethnic groups/organisations to identify the needs of disabled people from minority ethnic groups.**
- **DHSSPS, HSS Boards and Trusts in co-operation with disability groups and organisations and black and minority ethnic groups and organisations, should commission research and a needs assessment exercise on the health and social care needs of black and minority ethnic people with disabilities in Northern Ireland.**
- **DHSSPS, HSS Boards and Trust should work closely with disability groups and organisations and other relevant bodies and organisations to establish black and minority ethnic disability groups in Northern Ireland. People with disabilities from black and minority ethnic groups should,**

where possible, be identified and referred to such groups for support and advice.

- **DHSSPS, HSS Boards and Trusts must build a relationship with disabled people from black and minority ethnic communities in order to encourage them to access the services they require. This could involve a media campaign including the production of information packs in a range of different formats and languages.**
- **DHSSPS, HSS Boards and Trusts should conduct regular data collection of ethnicity and disability within the health and social services in order to both plan and monitor health and social services. However, the wishes of those who do not wish to disclose either their ethnicity or disability must be respected.**

Disability and Sexual Orientation

There is a scarcity of research regarding the interaction between disability and sexual orientation in Northern Ireland. As a result very little is known about the experiences of lesbian, gay and bisexual (LGB) disabled people in accessing health and social services.

Many lessons, however, can be drawn from a recent qualitative research study conducted by Brothers (2003) which explores the social profile and experiences of LGB disabled people in Ireland. The study highlights, for example, that “coming out” to health and social care professionals can be especially difficult for disabled people because health and social care personnel, and society in general, often hold the view that disabled people are asexual. This point is particularly well illustrated by one participant in the study who stated that:

“.....The GP just wouldn't ask you about your sexuality because [the GP thinks] disabled people don't have sex. If you were to announce “I'm gay” they would probably just think that you were having an identity crisis, you were schizophrenic or seeking attention!” (Brothers, 2003:60)

Brothers (2003:59) suggests that the health and social care sector has made little effort to take into account the lives and needs of LGB disabled people and noted a lack of understanding amongst many health and social care staff. A number of consistent problems experienced by LGB disabled people in access to, and use of, health and social services have been identified and include:

- the homophobic attitudes of some health and social care staff (Brothers, 2003:59);
- a lack of access to appropriate **sexual health advice** (Brothers, 2003:53);
- the level of **social isolation** experienced by LGB disabled people living in **residential accommodation**; and,
- issues around **confidentiality** with many LGB disabled people expressing a reluctance to discuss their sexuality with health and social care professionals for fear that it would be relayed back to parents or carers (Brothers, 2003:61).

Social isolation is particularly profound for LGB people with disabilities. As Brothers (2003:57) notes, many LGB disabled people do not feel comfortable in either the disability movement or the LGB community. It is evident that health and social care commissioners and providers have a significant role to play not only in encouraging social inclusion but also in facilitating equal opportunities for disabled LGB people in relation to access and use of health and social services.

Brothers (2003) offers a number of recommendations for improving services for disabled LGB people. It is suggested that the DHSSPS and its associated bodies take into consideration how these recommendations could be applied in Northern Ireland.

Recommendations: Disability and Sexual Orientation (Brothers, 2003:70)

- **There is a need for further research on the needs and experiences of LGB disabled people. The research should focus on other dimensions of disability and identity**

including age, race, gender and religious belief.

- **Health and social care professionals require improved training and development to understand the experiences of LGB disabled people. Service providers must think across “labels” to develop an integrated approach to diversity issues.**
- **There is a need for the provision of concise information on issues facing LGB disabled service users, including an information directory issued to every GP practice and health centre. Detailed services available to LGB disabled people and information on other relevant organisations should be made available.**
- **Support should be given to assist the capacity of grass roots networking organisations to bring together LGB disabled people in order to identify and address the problem of social isolation.**
- **Disability, equality and human rights organisations should work together in partnership with public service providers to address negative attitudes about disability and sexual orientation in general practice and other areas of health and social care provision.**

Disability and Access to Information

In keeping with developments in Great Britain and the Republic of Ireland, an increasingly wide range of health and social care information is now available online in Northern Ireland. A number recent studies have, however, begun to assess the advantages and disadvantages of e-Government on the ability of disabled people to access information.

A survey by Pilling et al (2004), for example, examines whether the provision of goods, facilities and services through the Internet removes, or indeed adds to, many of the access barriers experienced by disabled people. The survey findings⁸⁷ confirm that internet access and online information and services are particularly valuable in facilitating access for, people who cannot leave their homes, people who have difficulties reading or writing common forms of print, and people with speech impairments.

However, Pilling et al (2004) also identify a number of barriers experienced by disabled people in accessing information and services through the internet including:

- the costs associated with purchasing technology (that is, the costs of buying a computer and other assistive devices, and the costs associated with internet access);
- in regards to assistive devices (for example, voice recognition, keyboard adaptations, mouse adaptations, speech output systems) there are difficulties with knowing what devices to use, and in getting advice and training on how to use them; and,
- the availability of suitable training in internet usage.

Pilling et al (2004) notes that these barriers may be particularly profound for older people with disabilities and those who are socially and economically disadvantaged.

Survey respondents made a number of suggestions as to how websites could be better designed to improve access for disabled people. These recommendations included clear summaries of website information and navigation instructions on the home page; less cluttered pages; fewer graphics and less advertising; easier to find links; and easily adjustable colour, type and font sizes.

It must be acknowledged that the DHSSPS, HSS Boards and Trusts and other agencies are already well aware of many of the barriers experienced by disabled people in accessing both online and hardcopy information. Many positive steps have been taken to improve service user's access to information and services.

⁸⁷ Findings relate to 193 completed questionnaires from enquirers to AbilityNet, a UK charity giving information and advice to disabled people on any aspect of computing. 136 were Internet users.

These include, for example, the development of accessible information guidelines in many HSS Trusts and Boards, and the emphasis on improving access to information for all citizens in the new HPSS Information and Communication Technology (ICT) Strategy.

Recommendations: Disability and Access to Information

- **DHSSPS should conduct a survey to assess disabled people's access to health and social service goods, facilities and services through the Internet. This exercise should include identifying means by which the DHSSPS, HSS Boards, & Trusts etc could be improved to make them more disabled user friendly.**
- **DHSSPS, HSS Boards & Trusts should explore the possibility of conducting Disability and Internet use campaign, providing computer facilities and training for disabled people in day centres, residential centres, hospitals and so on.**

Disability, Human Rights and Access to Health and Social Services

Research which explicitly focuses upon disability and human rights is still very much in its infancy in Northern Ireland which has resulted in a lack of available literature. This is particularly the case in regards to research which analyses the connections between disability, health and human rights.

The relationship between mental health and human rights is a theme which is perhaps most frequently documented. This issue has been recently explored in a report by the Northern Ireland Human Rights Commission (NIHRC) (2003) entitled "*Connecting Mental Health and Human Rights*". The NIHRC report provides a review of the human rights issues involved in mental health law, policy and practice in Northern Ireland and includes a number of recommendations aimed at better protecting and promoting the human rights of people with mental health problems.

Three particular types of situation are identified which the report suggests could give rise to human rights issues in mental health law, policy and practice. These situations in which:

- a person is **not mentally competent** to make a decision;
- a mentally competent person is **not willing to consent** to proposed care and/or treatment, and
- a person with mental health problems presents a **risk of harm to self and/or others** (NI Human Rights Commission, 2003:8).

The assessment and detention of people with mental health problems under mental health legislation in Northern Ireland is likely to raise a number of human rights issues. Article 5 (the right to liberty and security of the person) and Article 6 (the right to a fair trial) of the European Convention on Human Rights are of particular relevance in regards to this issue. The NIHRC report maintains that the current procedures for detention under mental health legislation in Northern Ireland do not appear to meet the standards of swiftness, independence and impartiality required by Articles 5 and 6 (NI Human Rights Commission, 2003:9).

Recommendation: Mental Health and Human Rights

- **DHSSPS should familiarise itself with the Northern Ireland Human Rights Commission Report “*Connecting Mental Health and Human Rights*”. The Department and its associated bodies and agencies should consider the recommendations of the report and its implications for health and social services.**

In addition to mental health, the 1998 Human Rights Act has significant implications for a wide range of other issues in relating to disability and the provision of health and social services in Northern Ireland. Ill-treatment or neglectful behaviour towards a person with disabilities in a health or social care setting, for example, may be in violation of Article 3 of the Convention (that is, the right not to be subjected to torture, inhumane or degrading treatment). Preventing a disabled person in a residential setting from engaging in a relationship with another resident, or preventing

disabled people from having or raising children, could impinge upon Article 12 (the right to marry and found a family) and Article 8 (the right to respect for private and family life).

Daw (2000), in a report entitled *“Human Rights and Disability: The Impact of the Human Rights Act on Disabled People”* provides an account of many other implications of the ECHR on health and social services. For example,

- **Article 2 (the right to life):** could be used to reinforce the rights of disabled people when resources are limited. For example, if a disabled person were refused treatment solely because of his/her disability (perhaps on the basis of assumptions about ‘poorer quality of life’) this may breach Article 2, together with Article 14.
- **Article 8 (the right to private and family life):** has far reaching implications for health and social services and is relevant to issues such as the use of mixed sex wards, the right to consent to medical examinations, the right to confidentiality, the right to independent living and could be used to cover a right to access medical and other related records.

These are just a few illustrations of the implications of the European Convention on Human Rights on access to health and social care for people with disabilities. However, there is clearly a need for more Northern Ireland-based research which will identify additional human rights implications for health, social services and public safety policy, practice and procedures.

Recommendations: Disability and Human Rights

- **Research should be commissioned on the impact of the Human Rights Act for disabled people in Northern Ireland.**
- **DHSSPS, Boards and Trusts should continue to raise awareness of disability and human rights issues through staff training. Steps must be taken to further promote a “human rights culture” in HPSS services and amongst HPSS staff.**

- **DHSSPS, HSS Boards and Trusts should encourage HPSS facilities (e.g. hospitals, residential homes, day centres) to review their policies and procedures in a bid to identify areas which are in potential violation of the human rights of disabled people.**

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Useful Web-Links*

Alzheimer's Disease

- **Alzheimer's Society** - UK's leading care and research charity for people with dementia, their families and carers.
www.alzheimers.org.uk

Arthritis

- **Arthritis Care** - voluntary organisation working with and for people with arthritis.
www.arthritiscare.org.uk
- **Arthritis Research** – arthritis research portal
<http://arthritis-research.com>
- **Arthritis Research Campaign** - promotes medical research into the cause, treatment and cure of arthritic conditions.
www.arc.org.uk

Autism Spectrum Disorders

- **Autistic Society** - mission is to unite parents, families, friends, people with Autism and professionals by creating a strong, [supportive community](http://www.autisticsociety.org) worldwide. Sharing first hand knowledge, information, news and research about Autistic Spectrum Disorders.
www.autisticsociety.org
- **Centre for the Study of Autism** – US website provides information about autism to parents and professionals, and conducts research on the efficacy of various therapeutic interventions.

www.autism.org

- **National Autistic Society** – champions the rights and interests of all people with autism ensuring that they and their families receive quality services appropriate to their needs.
www.nas.org.uk
- **PAPA** – Parents and Professionals and Autism (PAPA) Northern Ireland charity for autism and Asperger’s Syndrome.
www.autismni.org

Cancer

- **Action Cancer** – Northern Ireland cancer charity providing early detection services, counselling and support services, research, cancer prevention and health promotion.
www.actioncancer.org
- **Breast Cancer Care** – UK's leading provider of information, practical assistance and emotional support for anyone affected by breast cancer.
www.breastcancercare.org.uk/
- **Cancer Research UK** – largest volunteer-supported [cancer research organisation](#) in the world and we support the work of 3,000 scientists working across the UK.
www.cancerresearchuk.org/
- **Ulster Cancer Foundation** – aims to help patients and their families cope with cancer.
www.ulstercancer.org
- **Macmillan Cancer Relief** - UK charity that works to improve the quality of life for people living with cancer.
www.macmillan.org.uk
- **Marie Curie Cancer Care** – charity which provides care for cancer patients and their families.
www.mariecurie.org.uk

- **Sargent Cancer Care for Children** - strives to help children and young adults diagnosed with cancer and their families.
www.sargent.org/

Diabetes

- **Diabetes UK** – leading charity working for people with diabetes.
www.diabetes.org.uk

Drugs & Alcohol

- **Alcohol Concern** - national agency on alcohol misuse.
www.alcoholconcern.org.uk
- **Drugs Prevention** – Northern Ireland regional drugs and alcohol website for professionals, includes the latest research, information and statistics on drugs and alcohol use.
www.drugsprevention.net

Eating Disorders

- **Eating Disorders Association** – information and help on all aspects of eating disorders including Anorexia Nervosa, Bulimia Nervosa, Binge Eating Disorder and related eating disorders.
www.edauk.com

Epilepsy

- **Epilepsy Action** – acts as the voice for the UK's estimated 440,000 people with epilepsy, as well as their friends, families, carers, health professionals.
www.epilepsy.org.uk

Heart & Lung

- **British Heart Foundation** – plays a leading role in the fight against heart disease.
www.bhf.org.uk

- **British Lung Foundation** – UK charity that focuses on and tackles all aspects of lung conditions.
www.lunguk.org
- **NI Chest, Heart & Stroke Association** – promotes the prevention of and alleviate the suffering resulting from chest heart and stroke related illnesses.
www.nichsa.com

HIV & AIDS

- **Terrence Higgins Trust** - leading HIV & AIDS charity in the UK
www.tht.org.uk/
- **National AIDS Trust** – HIV and AIDS policy development and campaigning organisation.
www.nat.org.uk

Learning Disability

- **British Institute of Learning Disabilities** – committed to improving the quality of life for people in the UK with learning disabilities.
www.bild.org.uk
- **Down Syndrome Association** - provides information and support for people with Down's syndrome, their families and carers as well as professionals. www.downs-syndrome.org.uk
- **Family Fund** - registered charity covering the whole of the UK funded by the national governments of England, Northern Ireland, Scotland and Wales. Working towards an inclusive society where families with severely disabled or seriously ill children have choices and the opportunity to enjoy ordinary life.
www.familyfund.org.uk/

- **Foundation for People with Learning Disabilities** - works with people and their families to ensure they can use effective services, play a fuller part in communities and society, and enjoy equal rights.
www.learningdisabilities.org.uk
- **Phab Northern Ireland** - offers young people over the age of 16 years the opportunity to experience living independently, with individual support and training.
www.phabni.org
- **Mencap** – UK learning disability charity working with people with learning disabilities, their families, and carers. Campaigning for equal rights and challenging discrimination.
www.mencap.org.uk

Mental Health

- **Action Mental Health** – largest regional voluntary sector organisation in the UK offering rehabilitation and training to people suffering with, or recovering from mental illness.
www.actionmentalhealth.org.uk
- **Young Minds** - the national charity committed to improving the mental health of all babies, children and young people.
www.youngminds.org.uk
- **Northern Ireland Association for Mental Health** – provides local support for those with mental health needs and offers a wide range of services including housing schemes, day care provision and advocacy.
www.niamh.co.uk
- **MIND** – leading mental health charity in England and Wales working towards creating a better life for those experiencing mental distress.
www.mind.org.uk
- **SANE** – committed to providing crisis care and information about mental health to people of all ages.
www.sane.org.uk

- **Samaritans** – confidential 24 hour helpline.
www.samaritans.org.uk
- **Mental Health Foundation** - aims to help people survive, recover from and prevent mental health problems.
www.mhf.org.uk
- **Mental Health in Later Life** – provides information on dementia, substance misuse, depression etc.
www.mhilli.org
- **Rethink** - dedicated to improving the lives of everyone affected by severe mental illness, formerly known as the National Schizophrenic Fellowship.
www.rethink.org
- **Review of Mental Health & Learning Disability** - independent review examining the law, policy and provisions affecting people with mental health needs or a learning disability in Northern Ireland.
www.rmhdni.gov.uk

Visual and Hearing Impairments

- **Action for Blind People** – enables blind and partially sighted people to transform their lives through work, housing, leisure and support.
www.afbp.org
- **Blind Centre for Northern Ireland** – local society which provides direct services to blind and visually impaired people of all ages.
www.bcni.co.uk
- **British Deaf Association** - national organisation run by Deaf people, for Deaf people.
www.britishdeafassociation.org.uk

- **Deafblind UK** - a national charity which provides a range of support services to deafblind adults and their carers. It also campaigns on behalf of deafblind people.
www.deafblind.org.uk
- **Royal National Institute for the Blind** - UK's leading charity offering information, support and advice to over two million people with sight problems. www.rnib.org.uk
- **Royal National Institute for Deaf and Hard of Hearing People** - largest charity representing deaf and hard of hearing people in the UK.
www.rnid.org.uk
- **National Blind Children's Society** – provides support for blind and partially sighted children and their families.
www.nbcs.org.uk
- **National Deaf Children's Society** – organisation of parents, families and carers which exists to support parents in enabling their child to maximise their skills and abilities.
www.ndcs.org.uk

Speech & Language

- **Afasic** – aims to help children, young people and their families affected by the hidden disability of speech, language and communication impairments -www.afasic.org.uk
- **Speechmatters** – Northern Ireland based voluntary organisation working to promote quality of life and opportunity for adults who have become aphasic.
www.speechmatters.org

Other

- **Association for Spina Bifida** - national organisation providing information and advice about spina bifida and hydrocephalus to individuals, families and carers - www.asbah.org

- **Action for ME** - UK's leading charity dedicated to improving the lives of people with M.E.
www.afme.org.uk
- **Brain Injury Association** – aims to promote understanding of all aspects of brain injury; and to provide information, support and services to people with a brain injury, their families and carers.
www.headway.org.uk
- **British Brain & Spine Foundation** – set up to develop research, education and information programmes aimed at improving the prevention, treatment and care of people affected by disorders of the brain and spine.
www.bbsf.org.uk
- **Brittle Bone Society** – supports children and adults with brittle bone conditions.
www.brittlebone.org
- **Disability Action** – works to ensure that people with disabilities attain their full rights as citizens, by supporting inclusion, influencing Government policy and changing attitudes in partnership with disabled people.
www.disabilityaction.org
- **Disability Rights Commission** – independent body established to eliminate discrimination against disabled people and to promote equality of opportunity.
www.drc-gb.org
- **Dyspraxia Foundation** – charity which aims to help people understand and cope with dyspraxia.
www.dyspraxiafoundation.org.uk
- **Haemophilia Society** - working for people with haemophilia, von Willebrand's or a related bleeding disorder and their families.
www.haemophilia.org.uk
- **ME Association** - funding and supporting research and providing information and support, education and training in relation to M. E. - www.meassociation.org.uk

- **Motor Neurone Disease Association** - only national organisation in England, Wales and Northern Ireland dedicated to the support of people with MND and those who care for them. www.mndassociation.org
- **Multiple Sclerosis Trust** - leading independent charity for people with multiple sclerosis, their family and friends and for all health professionals. www.mstrust.org.uk
- **Praxis** – Northern Ireland based charity which provides services for adults and children with a learning disability, mental ill health, acquired brain injury, and older people. www.praxiscaregroup.org.uk
- **SCOPE** – supports people with cerebral palsy in areas relating to early years, education, daily life and work. www.scope.org.uk

*Please note that this is NOT a definitive list of relevant websites